

Practitioner's Guide #4

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Addressing the Health Literacy Needs of Adult Education Students¹

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Introduction

Approximately 80 million adults in the United States have limited health literacy (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Kutner, Greenburg, Jin, & Paulsen, 2006). Consequently, the health information, understanding, and resources needed to manage their own or their family members' health are not available to them, often leading to negative health outcomes. Low health literacy is most common among people of color, non-native English speakers, and people with limited income and schooling (Heinrich, 2012; Kalichman & Rompa, 2000; Kaphingst, Goodman, Pyke, Stafford, & Lachance, 2012; Rothman et al., 2006).

Learners in adult education and family literacy (AEFL) programs mirror these demographics. Having children also requires parents to engage in new health literacy practices such as completing health history forms, making decisions about vaccinations, installing car seats, and managing children's health (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 24). As such, AEFL educators can play a key role in teaching and enhancing health literacy. The purpose of this guide is to inform practitioners about the current descriptions of health literacy, the relevance of the topic to AEFL practice, and ways to incorporate health literacy into the classroom.

What Is Health Literacy?

The National Library of Medicine's widely used definition states that is "the degree to which individuals have the capacity to obtain, process, and understand basic

health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, qtd. in Selden et al., 2000, p. vi). This definition is situated in the once-dominant view of health literacy, which focuses on individual, functional skills such as reading medicine labels. This "clinical" (Pleasant & Kuruvilla, 2008) or "medical literacy" (Peerson & Saunders, 2009) approach is concerned with "cognitive capabilities, skills and behaviors which reflect an individual's capacity to function in the role of a patient within the healthcare system" (Sørensen et al., 2012, p. 4).

Recent discussions of health literacy have sought to correct the shortcomings of this view. Namely, it is too focused on individual skills and reading comprehension, it defines health literacy as a risk instead of an asset or resource, it places the main responsibility for health outcomes on individuals, its goal is to create compliant patients, and it ignores social conditions that can limit access to healthcare (e.g., employment, income) and to the types of literacy needed to navigate the healthcare system (see e.g., Chinn, 2011; Nutbeam, 2008, 2009; Peerson & Saunders, 2009; Ronson & Rootman, 2012).

A broader view of health literacy, which defines it as a dynamic social practice that is always situated in specific sociocultural settings (e.g., Nutbeam, 2008; Papen, 2009), has gained more acceptance. This "public health" (Pleasant & Kuruvilla, 2008) or "asset" (Nutbeam, 2008) perspective frames health literacy as a resource that equips people to navigate healthcare systems, critically assess information, and take more control of their health. Within this framework, health liter-

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acy is a shared responsibility of individuals, healthcare systems, and healthcare practitioners, who should create accessible healthcare systems and learn to use effective oral and written communication to meet patients' needs (Coleman et al., 2011; Ronson & Rootman, 2012; Sherow & Weinberger, 2002). It is also a shared resource, meaning that people exchange knowledge, interpret health information, and make healthcare decisions with help from family and friends (Papen, 2009).

In sum, "critical health literacy" transcends functional health knowledge by "rais[ing] awareness of the social, economic, and environmental determinants of health" (Nutbeam, 2000, p. 364). Combined with health knowledge and skills, this awareness helps people understand how education, income, race, environmental and community conditions, and other social structures cause health disparities (Chinn, 2011). Together, people can examine ways to challenge social inequities, advocate for their health needs, and improve health outcomes for individuals and communities (Chinn, 2011; Nutbeam, 2000). Wills (2009) summarized the difference between the two models thus: "Being able to read a food label one thing, understanding why a Macdonalds [sic] is so cheap, filling and ubiquitous is another" (p. 4).

The following comprehensive definition of health literacy includes both functional and critical dimensions:

Health literacy is linked to literacy and entails people's knowledge, motivation and competences [sic] to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (Sørensen et al., 2012, p. 3)

Beliefs about the causes of individual health literacy status are debated as much as the concept itself. Some of these precursors include "demographic, psychosocial, and cultural factors, as well as...more proximal factors such as general literacy, individual characteristics and prior experience with illness and the healthcare system" (Sørensen et al., 2012, p. 7). The sociocultural setting also influences individual health literacy, for example, the print-saturated healthcare environment (e.g., informational brochures, charts, prescriptions), the power inherent in the profession-

al's position (p. 24), and "institutional processes and practices" such as completing forms to explain illness or to request additional assistance beyond the primary care doctor (Papen, 2009). The nature of health information and the types of literacy required to navigate the healthcare system are rapidly changing. This suggests that health literacy is active and dynamic (Kickbusch, Wait, & Maag, 2005, p. 9).

Why Should Adult and Family Literacy Educators Be Concerned about Health Literacy?

Prevalence of Health Literacy

Educators should be concerned about health literacy because low health literacy is prevalent among the very groups that are common in AEFL classrooms: people in poverty, people of color, adults with limited schooling, and struggling readers and writers. In particular, adult learners need to understand myriad changes in healthcare policies, rights, and other information tied to the Affordable Care Act.

Results from the 2003 National Assessment of Adult Literacy (NAAL) health literacy component showed that 22% of adults had *basic* health literacy levels, such as finding information in a document about why a person without symptoms might require tests for a particular disease (Kutner et al., 2006). Another 14% of adults had *below basic* levels, such as reading a document to locate the date of a medical appointment.

These skills are important yet insufficient to fully participate in the U.S. healthcare system or to advocate for the health of oneself and family members. In addition, test questions about print or health literacy "may bear no relation to people's actual everyday practices" (Hamilton & Barton, 2000, p. 383), since people may have strategies for understanding written health information and navigating the healthcare system that tests such as the NAAL may not capture.

Various tests are used to assess health literacy levels, including the Rapid Estimate of Adult Literacy in Medicine, the Test of Functional Health Literacy in Adults, and the Newest Vital Sign, among others. These tests are widely used, but accurate measurement of health literacy is difficult to obtain because current assessment tools are limited: They "primarily measure reading skills, and...not...other critical skills" (Nielsen-Bohlman et al., 2004, p. 5) that adults use to acquire



and interpret health information such as writing and critical media literacy. Furthermore, current tests tend to measure individual skills in isolation, ignore contextual factors that might influence comprehension such as "health professionals' communication skills and the use of technical language" (Green, 2007, p. 12), and neglect skills that patients consider vital to health literacy, including verbal communication, assertiveness, and knowing when and where to seek health information (Jordan, Buchbinder, & Osborne, 2010).

The flaws of these standardized tests notwithstanding, studies show that low health literacy (LHL) is often associated with the following demographic factors:

- Race/Ethnicity: Kaphingst and colleagues (2012) found a significant difference between the health literacy of white and non-white participants (p. 38). Specifically, African Americans are more likely to have marginal or low print and health literacy skills than other racial groups (see also Osborn, Paasche-Orlow, Davis, & Wolf, 2007; Rothman et al., 2006). For instance, 24.4% of Blacks in one study had low health literacy compared to 9.7% of whites (Chaudhry et al., 2011).
- Native Language: According to the 2003 NAAL, adults who spoke a language other than English before entering school had lower health literacy (Kutner et al., 2006, p. 12). Latinos in Britigan and colleagues' (2009) study listed language as a barrier to accessing health information.
- Income: LHL is more common among low-income than higher-income groups (Kutner et al., 2006; Rothman et al., 2006). Kalichman and Rompa (2000) found that 94% of those with LHL in their study earned less than \$20,000 per year.
- Educational Attainment: Health literacy levels are significantly correlated with educational attainment (Heinrich, 2012; Kutner et al., 2006; Parikh, Parker, Nurss, Baker, & Williams, 1996). High school completion seems to be a threshold for obtaining useful levels of health literacy. One study found that 79% of those with LHL had less than a high-school education, compared to 50% of those with higher health literacy levels (Kalichman & Rompa, 2000, p. 340).

In sum, health literacy is a social justice issue that affects marginalized groups (Hill, 2004).

These factors can be related to low health literacy in a variety of ways. For example, educational attainment can influence employment, income, and access to adequate housing. Affordable housing is often located in areas with high risk factors such as exposure to toxins and limited availability of quality healthcare. Societal factors such as institutional structures and discrimination can shape educational opportunities for racial and ethnic minorities, thus limiting the development of health knowledge and skills. However, determining the exact ways in which these demographic factors contribute to health literacy is a source of great debate.

Consequences of Low Health Literacy

Low health literacy has been shown to affect the health and well-being of individuals, families, and communities. These consequences "have grown as patients are asked to assume more responsibility for self-care in a complex health care system" (Selden, Zorn, Ratzan, & Parker, 2000, p. v). Difficulties include:

- completing functional tasks such as filling out patient registration forms (Sarfaty, Turner, & Damotta, 2005, p. 305),
- reading and using medication labels (Ronson & Rootman, 2012; Sarfaty et al., 2005),
- interacting with healthcare professionals (Sarfaty et al., 2005),
- accessing insurance programs (Diehl, 2011), and
- identifying high-quality health information (Shaw, Huebner, Armin, Orzech, & Vivian, 2009).

LHL has also been linked with health disparities. When patients and healthcare providers have different racial/ethnic or linguistic backgrounds, LHL can exacerbate communication problems (Sherow & Weinberger, 2002). In addition to language barriers, practitioners' and patients' cultural beliefs about disease, prevention, and treatment can lead to misunderstandings (Shaw et al., 2009; Villaire & Mayer, 2008), resulting in distrust of medical personnel, worsening health conditions, and even death. Educators are encouraged to read *The Spirit Catches You and You Fall Down* (Fadiman, 1997) to explore the intersection of health and the cultural beliefs of patients and professionals.



Connections to Print Literacy

From a functional perspective, general literacy abilities and health literacy levels are directly related (Rudd, 2007). A sociocultural framework, however, considers how social structures influence both print and health literacy. As mentioned above, general literacy abilities relate to health because they influence other life factors such as employment and living conditions (Hill, 2010; Ronson & Rootman, 2012). Health literacy, on the other hand, may influence "short-term...health behaviors and decisions" (Ronson & Rootman, 2012, p. 110) such as accurately reading and understanding a prescription drug label or measuring medications.

Health literacy is also situation-specific (Papen, 2009). People who read and write with ease may have difficulty understanding health information on a newly diagnosed or unfamiliar disease or treatment regimen (Villaire & Mayer, 2008, p. 6). This is partly due to the reading level of published health materials, many of which "are written at reading grade levels that exceed the reading skills of an average high school graduate" (Rudd, 2007, p. S8). This also applies to health information for child caregivers:

Despite clear standards for developing and delivering low-literacy health information and specific advice from parents with limited health literacy to make materials more clear, most written child health information is written above the eighthgrade level—the median grade level of US adults. (Sanders, Federico, Klass, Abrams, & Dreyer, 2009, p. 136)

Although many factors influence health literacy, increased general literacy abilities can enhance the likelihood of accessing and understanding written health-related information. In sum, print literacy is a necessary but insufficient component of health literacy.

Addressing Health Literacy in AEFL

Some of the causes of low health literacy, such as the structure of the U.S. healthcare system, the development and implementation of healthcare policies, and the training of medical professionals, are beyond the realm of AEFL educators' influence. Nevertheless, educators have an important role to play in enhancing health literacy among program participants.

Examples of Success

AEFL educators have used various methods to address concerns about low health literacy. Some focus on improving functional literacy and health knowledge, whereas others employ participatory models that create partnerships with healthcare providers and that equip students to take more control of their health. Initiated by a team of adult education and healthcare professionals, Health Literacy Study Circles+ aimed to help educators "learn about research findings, analyze issues..., and develop mechanisms for integrating new ideas and processes into their classrooms" (Rudd, 2004, p. 9). Study circles were piloted in New York, Massachusetts, and Louisiana. Instead of transmitting information to educators, teachers collaborated on lesson plans, practiced teaching techniques, and shared ideas for identifying and addressing their students' health literacy needs. A guidebook, including sample lessons and suggestions for conducting needs assessments and developing health literacy units, is available online (Soricone, Rudd, Santos, & Capistrant, 2007).

An experimental study in Illinois included 42 adult basic education (ABE) and English for Speakers of Other Language (ESOL) programs with more than 2,000 students participating (Levy et al., 2008). Healthcare, social work, adult education, and curriculum experts determined relevant topics and objectives, which were used to develop an experimental health literacy curriculum. Randomly assigned program sites used the experimental curriculum, while control group sites continued with their regular curricula. After 42 weeks, the reading scores of students in the experimental group "increased at least as much and usually more" than those in the control group (Levy et al., 2008, p. 37). Health literacy scores were even more dramatically affected: "The adults significantly improved their health knowledge and skills in every literacy level in ABE and ESOL through the experimental curriculum. The participants in the control sites had no change in the health knowledge/ skills" (Levy et al., 2008, p. 37).

Hohn (1998) worked with adult education student leaders in Massachusetts to choose health topics and develop multi-part programs that were taught to over 150 adult students during a four-month period. Acting as a facilitator, Hohn required student leaders to take responsibility for learning necessary health information, devising teaching strategies, and implementing



the resulting lessons. In addition to specific health lessons, the group developed a four-part process to apply to future health education: "(a) providing basic information, (b) hands-on activities for teaching skills and tools, (c) drama to bring out difficult issues for discussion, and (d) providing and discussing resources for the next steps or for obtaining further assistance" (p. 81). This type of power-sharing allowed student leaders to develop their ability to lead and take control, both inside and outside the classroom. They also learned valuable health information within a literacy context, while being equipped to address broader social implications of health such as discrimination, poverty, and limited access to resources. The project illustrates how both functional and social dimensions of health literacy can be addressed simultaneously.

Other groups have initiated similar participatory approaches. For example, low-income women in a Canadian adult literacy program collaborated to learn about relevant health topics such as stress, exercise, and healthy eating on a low budget (Norton & Horne, 1998). Subsequently, the participants described behavioral changes and increased understanding of the link between income and health. Interestingly, they "placed high value on making connections with each other and sharing support with others in the group" (Norton & Horne, 1998, p. 247), illustrating the shared nature of health literacy (Papen, 2009).

Generational differences were leveraged in a project about Canadian aboriginal health literacy (Antone & Ronson, 2009, as cited in Ronson & Rootman, 2012, p. 115). Senior adults read aboriginal-authored books with children and shared their insights about "culture...and health from an aboriginal perspective" (Ronson & Rootman, 2012, p. 115).

The New York City Health Literacy Fellowship is a unique example of collaboration between adult education and healthcare professionals (Tassi & Ashraf, 2008). Ten medical students completing their first year of study served as adult education volunteers by teaching literacy and health classes. After the 8-week program, the medical students reported an increased understanding of the relationship between health and literacy and ways to address the issue in their practice. All participants benefited from sustained personal contact, helping to "humanize" healthcare professionals and their future patients (Tassi & Ashraf, 2008, p. 7).

Further Suggestions

In addition to developing health literacy programs and curricula, AEFL practitioners can incorporate health literacy topics into their established curricula.

Teach Health Information

For many ESOL educators, integrating health literacy is a logical step because several required Comprehensive Adult Student Assessment Systems (CASAS) competencies address health topics (Diehl, 2011, p. 32). For example, educators' lesson plans may already include topics such as describing illness symptoms, interpreting doctor's directions, and locating community health resources. Explicit information about common illness or disease prevention and treatment can be added to the AEFL curriculum or integrated as a topic during literacy instruction (Witte, 2010). Educators should consider surveying students to determine primary areas of need or interest. If necessary, educators can obtain current health information from local healthcare professionals before designing lessons. Additional guidance is available from online sources such as Skilled for Health (Department of Health & Department for Business Innovation and Skills, 2013).

The following recommendations can help educators successfully teach health information.

- Intersperse health topics throughout the curriculum rather than isolating them to one unit of study (Levy et al., 2008).
- To build confidence in teaching health topics, establish partnerships with community health care practitioners and other resources (Diehl, 2004, 2011). Rosalie's Neighborhood: Let's Smile! A Book about Dental Health (Goodling Institute for Research in Family Literacy, 2012) is an example of curriculum developed through collaboration. Developed by the Goodling Institute at Penn State and the National Institute for Dental and Craniofacial Research, the curriculum's purpose is to provide oral health information to parents of young children. Rosalie's Neighborhood is the primary text, divided into short sections and written at a fourth grade level, which allows parents with limited literacy to improve reading skills while learning about child dental health. Lesson plans, printable activities, and a facilitator's guide are provided. Take



Charge of Your Health is another example of a collaboratively developed curriculum aimed at mothers with premature infants (Bennett, Pinder, Szesniak, & Culhane, 2008). Home visits were especially effective in reaching women who would not otherwise attend adult education classes.

Teach health information in a culturally-sensitive and safe manner (Greenberg, 2001). Learners' and educators' cultural and social backgrounds influence their beliefs and understandings of health, wellness, and treatment. Potential differences need to be recognized when making decisions about what to teach and how to teach it. For example, adult learners in Papen's (2009) study viewed health topics as important, but private. They did not want to discuss such issues in large, mixedgender classes. Educators working with African Americans should recognize that decades of egregious mistreatment and neglect by medical researchers and providers has contributed to a deep-seated mistrust of the medical establishment (Skloot, 2010; Washington, 2008).

Teach General Literacy Skills

In addition to teaching about specific health topics, educators can teach *general* literacy skills that support health literacy. Papen (2009) offers the following examples of relevant general literacy skills:

- Internet searching and critical reading and thinking skills enable students to access and evaluate health information pertinent to their lives.
- Giving opportunities to understand visual language such as pictures, charts, and symbols helps learners interpret medical information.
- Assertiveness training can help students to express their needs, desires, and frustrations to healthcare professionals.
- Encouraging students to share health information, resources, and strategies for finding information with each other may broaden the scope of health literacy abilities for all. "Health literacy is often 'distributed'....[I]t is not simply a property or an attribute of an individual, but...is shared knowledge and expertise. It resides in the patient's social network" (p. 27).

Use Authentic Texts

Educators can teach health-related information and literacy skills practically and simultaneously by using real-life, or authentic, health texts. For example, in lessons on scanning for information, understanding measurement, or summarizing key points of a text, teachers can use documents that learners encounter. such as prescription drug labels and accompanying information pamphlets, consent forms, patient privacy notices, websites, insurance enrollment forms, and informational brochures. Replicas of consent and informational forms required by medical and mental health providers can help students learn "not only how to decode and comprehend health-specific words but also what information is being conveyed by different texts and why it is important" (Nielsen-Bohlman et al., 2004, p. 157). Surveying students about their questions and concerns about health texts can help educators choose relevant materials.

Build Upon Students' Prior Knowledge

All adults, even those who struggle with health literacy, use a variety of strategies when facing difficult health-related tasks (Papen, 2009). Educators can discover, employ, and build on these strategies in the classroom. For example, many adults feel intimidated by healthcare professionals during office visits. Due to time constraints, doctors and nurses may provide information about health conditions and treatment too quickly or in an unclear way. According to Papen (2009), patients often prepare for visits by making lists of questions or important terms they want to discuss with the doctor. Following the appointment, they may seek information either to confirm or deny what they learned during the visit. Adults often use the knowledge and skills of family and friends to supplement their understanding of the health information they have received. In AEFL classrooms, these strategies can be shared among students and used as foundations for role plays or reading and writing activities.

<u>Partner with Healthcare Providers, Facilities,</u> and Researchers

Adult educators can address health literacy by developing partnerships with community healthcare providers and facilities (Witte, 2010). Healthcare professionals may be invited to give presentations about difficult or sensitive health topics to classrooms (Witte, 2010,



p. 10) or small groups of students, who can then teach the information to other students. Field trips to walk-in clinics, hospitals, or health fairs provide students with important information and relieve fear or discomfort with accessing healthcare sites. These interactions also help healthcare professionals gain new insights into typical adult health questions and effective communication (Witte, 2010, p. 9), which can help improve health literacy for all. AEFL educators can work with medical personnel to create accurate health materials written at lower reading levels (Diehl, 2004, p. 28). Examples include the Rosalie's Neighborhood curriculum, illness prevention informational brochures, and simplified forms including clear directions and reasons for requiring certain information.

Diehl (2011) describes innovative partnerships between AEFL programs and institutions such as community-based organizations, healthcare centers, health literacy councils, and physician groups. Educators can also partner with researchers or organizations that conduct and disseminate health literacy research. These types of collaboration can "break down the institutional, cultural, and professional silos that shape the way we think and act around health and literacy issues" (Gillis, 2004, p. 17).

Conclusion

People need health literacy abilities to flourish as "citizens, consumers, and patients" (Kickbusch et al., 2005, p. 12). To control personal and familial healthcare, we need to "access, understand, appraise, and apply health information" (Sørensen et al., 2012, p. 82). AEFL educators have a responsibility to address health literacy since adult learners are more likely to experience health disparities than people with more income and formal education. Taught independently or together, health information and general literacy skills can enhance adult learners' and caregivers' health literacy. Finally, by teaching critical health literacy, educators can equip learners to analyze health information, navigate healthcare systems, understand the social causes of health disparities, and work with others to advocate for health in their families, workplaces, and communities.

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Additional Resources

EL Civics Health Curriculum

http://www.ccs.k12.va.us/programs/esl/docs/health/ Health Curriculum.pdf

Georgia's Adult Education Health Literacy Toolkit http://georgiaoalregions.tripod.com/healthtoolkit/

Health Education and Adult Literacy: Breast and Cervical Cancer Curriculum

http://healthliteracy.worlded.org/heal/healBccHtml/index.htm

Health Literacy in Adult Basic Education: Designing Lessons, Units, and Evaluation Plans for an Integrated Curriculum

http://www.hsph.harvard.edu/healthliteracy/files/2012/09/healthliteracyinadulteducation.pdf

Health Literacy Special Collection http://www.healthliteracy.worlded.org/

Integrating Health Across the Curriculum http://www.sabes.org/curriculum/integrating-health-curriculum.pdf

Medicines in My Home

http://www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/UnderstandingOver-the-CounterMedicines/ucm092139.htm

Medline Plus

http://www.nlm.nih.gov/medlineplus/all_easytoread.html

Picture Stories for Adult ESL Health Literacy http://www.cal.org/caela/esl_resources/Health/ healthindex.html

Plain Language Website

http://www.plainlanguage.gov

Project SHINE: ESL Health Units

http://projectshine.org/resources/health-literacycurriculum

Skilled for Health

http://rwp.excellencegateway.org.uk/Embedded% 20Learning/Skilled%20for%20Health/



¹This practitioner's guide is drawn from the authors' forthcoming article on literacy and health disparities in *New Directions for Adult and Continuing Education*.